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ABSTRACT

This report evaluates a self-directed personal service (SDPS) program operated through the larger Enable Program for people with disabilities in Onondaga County, New York. First, it contrasts characteristics of traditional personal assistance services (such as low pay, agency-determined, limited types/levels of support, and program management through agencies) with characteristics of consumer-driven personal assistance services (including reasonable pay, person-determined, provision of whatever support is needed, and variety of program management options). Next, it describes potential personal assistance services in the areas of personal care, household, community, cognition, communication, mobility, infant and child care, and security and safety-enhancing services. The SDPS program allows people with disabilities to determine who provides assistance, what types of assistance are provided, and where and when the assistance is needed. Interviews with 16 SDPS participants found participants were: satisfied with the SDPS program; generally able to obtain the assistance they desired from the program; and dissatisfied with other services. Issues are identified, including support for people living in agency-controlled settings, program growth, provision of adequate pay and benefits to personal assistants, funding/management options, and availability to a diversity of people. (CR)

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EVALUATION OF THE

SELF-DIRECTED PERSONAL

SERVICES PROGRAM

OPERATED THROUGH ENABLE

Center on Human Policy

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EVALUATION OF THE SELF-DIRECTED PERSONAL SERVICES PROGRAM OPERATED THROUGH ENABLE

by
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April 1996

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From January 1995 to November 1995, the Center on Human Policy conducted an evaluation of the Self-Directed Personal Services (SDPS) program operated through Enable. This program offers personal assistance services to people with disabilities in Onondaga County. This report provides a brief introduction to the concept of personal assistance services; describes the SDPS program run through Enable; summarizes findings of the evaluation; and discusses constraints and challenges related to the larger service system.

PERSONAL ASSISTANCE SERVICES

Personal assistance services are supports that are designed to assist people to live in their own homes rather than institutions or other facilities. Across the country, such services have been provided in vastly differing ways. In a

traditional, medicalized model of home care, personal assistance services are provided by service agencies and encompass a narrow range of household and personal care activities determined in an assessment conducted by the agency. In contrast, many people with disabilities and advocates have argued for, and in some cases successfully developed, consumer-driven personal assistance services which encompass a broad array of supports, determined by the needs and desires of the individual with a disability (Centre for Research and Education in Human Services, 1990; Human Services Research Institute, 1991; World Institute on Disability, 1987). As described by the World Institute on Disability (1987, pp. 3, 4): "Personal assistance involves assistance with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole....Our conception of personal assistance services goes much deeper than a simple listing of tasks..." Table 1 illustrates some of the differences between a traditional medical model of home care and consumer-driven personal assistance services. Table 2 provides an example of a comprehensive range of personal assistance services.

TABLE 1

Some Components of Traditional versus Consumer-Driven Personal Assistance Services

Traditional	Consumer-Driven
low pay/may or may not get benefits	reasonable pay/benefits
agency-determined tasks/activities	person-determined tasks/activities
in-home supports	in-home and community supports
limited types/level of support	whatever support is needed
restriction on famly members as PCAs	no restriction on family members as PCAs
program management through agencies	variety of program management options
many people typically screened out (people with dd., medical, mental health labels, etc.)	inclusive of diverse people

TABLE 2

Sample Comprehensive Range of PAS Services

Personal services including, but not limited to, assistance with bathing and personal hygiene (including menstrual care), bowel and bladder care (including catheterization), dressing and grooming, transferring, eating, medication and injections, and operating respiratory equipment and other assistive devices.

Household services including, but not limited to, assistance with meal preparation, light and heavy cleaning, laundry, repairs, and maintenance.

Community services including, but not limited to, assistance with shopping, employment, education, participation in community and civic affairs, and leisure.

Cognitive services including, but not limited to, assistance with money management, scheduling, planning, cuing, and decision making.

Communication services including, but not limited to, interpreting, reading, and writing.

Mobility services in and out of the home including, but not limited to, escorting and driving.

Assistance with infant and child care.

Security and safety-enhancing services including, but not limited to, assistance with monitoring alarms and arranging for periodic in-person or telephone contacts.

Source: National Council on Independent Living. (1994). Position on personal assistance services. Author.

THE MISSION AND PROGRAM OF THE SDPS PROGRAM RUN THROUGH ENABLE

The SDPS program operated through Enable was established in 1992. Enable is an agency that provides a variety of services to people with developmental disabilities, such as early intervention, residential services, and supported work. Within a state where personal assistance services are typically controlled by service agencies and often limited to those with physical disabilities who do not have high levels of need for support, the people who established this program envisioned the opportunity for consumer control, as well as the inclusion of people with a wide range of needs and disabilities. Those who worked to establish the SDPS program at Enable included a group of people with disabilities who were dissatisfied with the services they received from home health care agencies. They wanted to offer a program that would allow people to determine who would provide assistance, to determine what types of assistance would be provided, and to determine where and when that assistance was needed.

Through Enable, personal care services are provided to 90 people in Onondaga County. SDPS is a program of the New York State Department of Social Services, for people who receive Medicaid and meet other eligibility requirements, operated through a contract from the Onondaga County Department of Social Services. According to state regulations covering this program,

all people who receive services must be eligible for Medicaid. In addition, regulations stipulate that participants must be medically stable and self-directing (or utilize a "self-directing other").

The SDPS program run through Enable receives most of its referrals for services from the county Department of Social Services' Long Term Care (LTC) office, other community agencies, or by word of mouth. When an individual approaches Enable with a request for personal assistance from SDPS, the program coordinator completes an intake form, assessing eligibility based on contractual requirements such as Medicaid eligibility, and then refers the individual to LTC. LTC then screens the individual to ensure that the person fits state criteria (e.g., medically stable, in need of care at home over a long period of time).

Once an individual is determined by LTC to be eligible for the program, staff at LTC conduct a task-based assessment to determine the number of hours of personal assistance service that a person will receive; then the person can hire assistants through the SDPS program. While staff at LTC consider program participants to be the employer of record, the assistants are on the Enable payroll and are provided with benefits and worker's compensation through Enable.

LTC pays for each hour of service rendered through SDPS, with differential rates set by DSS for higher levels of care. This rate also covers funding for administrative costs.

Although program participants can hire people of their choice, state regulations prohibit hiring a spouse, a parent, a son or daughter, and a mother- or father-in-law. In addition, state and county regulations mandate that PCAs complete an annual tuberculin test and a police check.

Enable maintains a list of possible assistants if program participants are unable to find one on their own; this list can also be used for back-up if a participant cannot find a replacement for a regularly scheduled assistant. It is assumed that participants will train their own assistants, since personal care is so variable based on each individual's wants and needs. Participants attend a training session led by the coordinator of SDPS where they discuss what kinds of questions to ask during an interview and how to supervise assistants. Although PCAs are not required to attend any training sessions, SDPS has made a videotape on techniques of care, such as how to lift properly, that is available to them.

The next section discusses the major findings of our evaluation of SDPS.

MAJOR FINDINGS

Themes drawn from interviews with program participants, assistants, administrators, county representatives, and others working in the human services form the basic findings of this

evaluation. The Appendix provides further detail about the research methodology.

1. Participants seem very satisfied with the SDPS program run through Enable. All of the participants we interviewed are satisfied with the services they receive from SDPS; most express extreme satisfaction. Perhaps the most important feature of the program is that people feel they have more control over their lives. As one participant commented, "Here, you know you have the power. I have control now." Participants highly appreciate having the ability to choose their own PCA and to determine when that person will assist them.

In addition, participants feel that the administration of SDPS is responsive to their needs. Several people mentioned that the program administrator promptly returns phone calls and is available to discuss dilemmas and help problem solve. As one person put it, "What's important to me is to have a responsive organization. Enable will work with you."

One person summed up her satisfaction with the program by stating, "I like living in my own place; I don't want to live in a nursing home." And another commented, "This program allows me the dignity to stay in my own home and to direct my own life."

2. Participants generally obtain the assistance they want and need. Most of the participants receive the amount and type of assistance they need from SDPS. However, some people, based upon LTC's determination, do not receive the number of hours they feel they need. While this is not a problem for everybody, it is

a major concern for some. Participants who require fewer hours of assistance per week tended to report more satisfaction with the amount of assistance than those who have high levels of need.

In addition, some people do not receive the type of support they need and desire, such as assistance with child care, community activities, and transportation. This is due to the limited task-based nature of this program.

3. Participants have a high degree of dissatisfaction with other services. Almost all of the participants in the SDPS program previously were served by a traditional home health care agency. Consumers are unable to supervise assistants in these agencies. Instead, they feel that the agency controls their lives. As one person put it, "They rule you." Another explained, for example, that if she needed a change in the way care was provided, she needed to tell a nurse from the agency, who would then tell the assistant.

One of the major complaints they had of other agencies was that they had no choice about who was sent as a PCA and little choice as to when this person would come. One person commented, "At one point, I had to deal with a different person every day of the week." Some participants had experiences with assistants who were unreliable and might not show up at all. At the same time, the agencies had difficulty finding back-up or replacements. For example, one participant remembered, "They had me go 13 days without aides."

4. Many people use their own networks or informal contacts for PCAs. According to the program participants, one of the most important aspects of SDPS is that they are able to choose their own PCAs. A few have found assistants through advertising in the newspaper, but most have selected friends, relatives, neighbors, or people they knew as staff members at other agencies. Although SDPS maintains a list of possible assistants, most people prefer to use their own networks. Many people have very personal needs, such as assistance with bathing, and this program allows them to choose people with whom they are comfortable. As one person put it, "I can choose people I trust."

Overall, it seems that satisfaction with the program is highly related to people's satisfaction with the specific PCAs they have at any given time. Most participants report very positive relationships with their PCAs. Many feel that they enjoy a much longer working relationship with PCAs when they are able to select them. In addition, they feel that the higher rate of pay offered by SDPS in comparison to most other home health care agencies enables them to both obtain and retain high quality support.

At the same time, people also have difficulties in hiring some people to be PCAs. For instance, participants reported that some people, whom they would have liked to hire, were unwilling to go through the hiring process of SDPS and particularly the police check, which they saw as demeaning. This limits the participants' choices of PCAs.

5. Some people have experienced problems in obtaining back-up help. Due to the program's emphasis on self-direction, participants have the responsibility to arrange their own back-up help when needed. While some participants have no problem with this, others find it difficult and are unable to obtain such support. While Enable sends participants a list of PCAs who are willing to do back-up, some people choose not to use the list, and others seem unaware of it. According to the coordinator of SDPS at Enable, several people who have inquired about the program decided to stay with a traditional agency rather than be responsible for finding their own back-up support. Some participants note that back-up help is difficult to obtain because of the requirements made of the PCAs by state and local regulations. For instance, some participants said that the people they would have chosen to provide back-up support to them were hesitant to fill out payroll forms and go through a police check and TB test.

6. PCAs generally seem satisfied with SDPS. Most of the PCAs interviewed report that they are satisfied with providing services to individuals through SDPS. Some of them had previously worked in traditional home health care agencies, whereas others had not. Those who had worked for other agencies noted a distinct difference in their roles, and a few were not comfortable with the self-direction which is the basis for the program. For example, one PCA who worked for SDPS and other traditional agencies reports that he is not comfortable with the

fact that the person he assists has the right to fire him, and he questions the participant's competence to do so.

Overall, however, PCAs who have not worked for other agencies, and many who have, tend to be enthusiastic about the program. Many PCAs say that they have a good relationship with the participant, they value the fact that this program enables people to have greater control over their own lives, and that they would not want to work for a traditional home health care agency. As one assistant commented, "I get to be the arms and legs for someone." Some assistants go beyond their prescribed roles; if they live in the neighborhood, they might stop by to see if the person needs anything. As another person put it, "I would do anything any time she needed me."

PCAs note that their pay is higher at this SDPS program run through Enable than at other local agencies. The program coordinator feels it is important for PCAs to receive as high a rate of pay as possible and notes that they are also able to offer health insurance and other benefits to full-time PCAs.

7. <u>The administration of SDPS at Enable is committed to its mission</u>. The program coordinator and assistant coordinator of SDPS at Enable are totally committed to providing a program where people with disabilities have the opportunity to be in control of their personal care assistance services. However, within the larger system, there are numerous constraints to a consumer-driven approach to services. These will be discussed in a later section of this report.

ISSUES AND CHALLENGES FOR ENABLE

Within the context of Enable's effort to provide self-directed personal assistance services, there are some issues and challenges that arise. These are outlined below.

1. Special consideration should be given to cases where SDPS supports people who are assisted by a "self-directing other." For some people, this works well, and they are assisted to make their own decisions and take control of their own lives. For other people, this may not work well, and they may be essentially under the control of their "self-directing other," whether this be a family member or another person.

Therefore, careful consideration needs to be given to use of a self-directing other, including the following:

- people should be presumed to be self-directing; a self-directing other should be utilized only when there is clear evidence of need for this;

- the self-directing other should be a family member, or close, unpaid friend, who is in regular contact with the person, and very familiar with his or her needs and preferences;

- the person with a disability should make the determination as to who is the self-directing other.

2. SDPS should not support people who live in agency-controlled settings. SDPS supports a few individuals who live in agency-controlled settings (e.g., group homes). The philosophy on which SDPS is based is incompatible with the orientation of

such settings. Thus, it is unlikely that SDPS support in an agency-controlled setting would significantly alter an individual's ability to control most dimensions of his or her life, thereby compromising the philosophy and practice of the SDPS program. In fact, it is unclear in such settings who is directing the personal care assistance. A challenge to SDPS, therefore, is to ensure that when they do enter into such a relationship with another agency, they are all working collaboratively to assist such individuals to move to homes of their own, in which they have real control.

3. The growth of the program should proceed carefully. Based upon signficiant demand for such a program, and lack of comparable alternatives locally, SDPS administrators envision expanding the number of people they serve. Currently, program participants report and value a high degree of responsiveness from administrators. There is a chance that some of this quality of the program may be sacrificed if too much growth occurs too rapidly. Therefore, a challenge is to ensure that responsiveness is maintained as the number of participants expands. An expansion in the number of agencies sponsoring self-directed personal assistance would make this program available to other people without placing unreasonable demands on SDPS administrators.

4. It will be important to maintain the energy to continue to push the system, together with other allies, over the long term. Based on its values of creating an inclusive, consumer-

driven program, on an ongoing basis SDPS administrators at Enable advocate for people with disabilities regarding issues of program eligibility (related to level of disability, issues of self-direction, health status, etc.), roles/tasks of PCAs, and adequate levels of support. Continued advocacy is necessary, as the system currently does not allow for truly consumer-driven services. This will require sustained energy from SDPS. SDPS administrators will need to consider whether they can advocate most effectively as part of a larger organization, or whether this would be enhanced by the creation of their own agency. In addition, it will be important for SDPS administrators to maintain their connection to allies who share their values and are supportive of their efforts, in the face of a larger system which has a different orientation and may be resistant to change.

SYSTEM CONSTRAINTS

Within New York State, the policy and implementation of personal care assistance services significantly limits the potential for a truly individualized, consumer-driven program. Illustration is provided with reference to general program characteristics outlined in Table 1. Each is discussed below, with examples drawn from this study.

1. Pay and benefits. Traditionally, across the country, personal care assistants earn very low pay, and sometimes receive no benefits, as well. This represents a societal devaluation of

people who have disabilities and those who support them. The quality of life for people with disabilities would be enhanced, in part, if PCAs received better pay and benefits (World Institute on Disability, 1987).

In Onondaga County, pay for home care is typically minimum wage, often with no benefits. Constraints within the system limit the degree to which Enable or any other agency can change this. At the same time, there is some flexibility within the system for agencies to make decisions affecting level of pay and benefits. For instance, Enable is making a significant effort to do what it can to increase the compensation for PCAs. The agency allocates a lower percentage of its funding than most agencies for administrative costs, passing along more to PCAs; offers benefits; and offers care for people with high levels of need at costs typically associated with those with lower levels of need.

2. Agency-determined versus person-determined duties of PCAs. People with disabilities should be presumed to know best what they need, and they should therefore be involved in determining what tasks PCAs assist them with (Centre for Research and Education in Human Services, 1991; Lyle O'Brien & O'Brien, 1992). Within New York State, the social services system limits this determination for people who receive personal care assistance, including those within the self-directed personal assistance service program, to a list of state Medicaid allowable tasks. In SDPS, people are involved in decisions about what

tasks will be performed and when, but the range of tasks is still restricted, based on the Medicaid allowable tasks criteria.

3. In-home only versus home and community supports. PCA programs should support people wherever they need supports to do the necessary things in their lives, in or outside of the home (National Council on Independent Living, 1994; World Institute on Disability, 1987). In New York State, personal care attendant services are typically restricted to the home. People interviewed for this study reported that with the traditional home care programs, their aides went shopping for them; they were not allowed to go out into the community with their aides. State guidelines for the SDPS program suggest that this too is a program that largely restricts support to people's homes. For example, one allowable task is: "Shopping for the patient, if no other arrangements are possible." The wording of this does not specificy whether the person with a disability is allowed to participate in this shopping. The program director notes instances in which PCAs have both been allowed and not allowed to accompany people in the community, and is unclear as to the basis upon which this is allowed or not allowed. In addition, the list of allowable tasks make no mention of other community activities such as appointments or banking, education, or participation in community and civic affairs.

4. Types and levels of support. Personal attendant service programs should provide people with whatever types and levels of support they need to remain in their own homes (Lyle O'Brien &

O'Brien, 1991; WID, 1987). Within New York State's personal attendant services program, the list of allowable support tasks is narrow, for example, including only light housework and not heavy, and with no mention of tasks related to dimensions of life such as communication, child-care, or civic and community involvements.

It is positive in New York State that there is no official cap on the number of hours of support that a person can receive. However, within this study, some people who require high levels of support report not receiving as many hours as they feel they need and are having to advocate for more.

5. Family members as aides. People with disabilities should be permitted to employ family members as PCAs if they so choose (Lyle O'Brien & O'Brien, 1991; WID, 1987). In many traditional home care service agencies, family members are not allowed to be paid for the provision of care. State guidelines for SDPS are more flexible, though they still contain significant restriction; they permit employment of some family members, but not others (e.g., a spouse, parent, child, mother-in-law, or father-in-law are excluded).

6. A range of funding/management options. Consumers should have a range of options available for managing their personal assistance service, from a direct cash payment model in which they manage their own services, to a model in which an agency assumes some responsibility for this in consultation with the person (NCIL, 1994; WID, 1987).

Within New York State, most personal assistance services are provided through agencies which assume control over the management of services. The SDPS program provides the opportunity for people to have control over some aspects of the program (e.g., hiring and firing PCAs) and limits their control over others (e.g., determining what PCAs will assist them with, since this determination is limited to Medicaid allowable tasks). This program channels funding for supports through agencies; in New York State, there is currently not available an option for people with disabilities to manage their personal assistance services on their own, or to receive partial assistance with management.

7. Available to a diversity of people. It has been argued that personal assistance services should be available to all people, with no exclusion based upon health/medical status, type of disability, age, and so forth (Kennedy, 1991; NCIL, 1994; WID, 1987). Currently, within New York State, guidelines screen out people based upon medical stability. The program coordinator of SDPS at Enable has advocated for the inclusion of people who may not be considered medically stable (e.g., some people who have medical fluctuations related to AIDS).

In addition, typical personal care assistance programs often have been oriented toward people only with physical disabilities and exclude people with mental retardation, mental health labels, or those with severe and multiple disabilities (Kennedy, 1991). It is notable that some people who fall into these commonly

excluded categories have been included in the SDPS program run through Enable. Participants have disabilities that include autism, mental retardation, multiple sclerosis, cerebral palsy, blindness, AIDS, and Alzheimer's disease. Enable staff particularly value and advocate for the inclusion of such people within the program.

CONCLUSION

Based on this study, most people who receive services are very satisfied with the SDPS program. Within this program, they have much more control than within traditional home care programs, and because of this, the support they receive is generally of a higher quality.

In its provision of this program, Enable offers many people with disabilities the opportunity to gain more control over the services they receive. However, those who were involved in starting the SDPS program that runs through Enable envisioned something different; that is, a truly consumer-driven attendant service program. This vision was based upon the experiences and desires of people with disabilities, as well as various examples, throughout the country, of consumer-driven services. The realization of this vision is currently not possible within New York State.

While state guidelines for and implementation of SDPS contain some elements of consumer control, they currently do not

allow the opportunity for truly consumer-driven services. There are many examples around the country which could be used in the establishment of such a program within New York State. While this program is a step in the right direction, a challenge for people with disabilities and advocates is to continue their efforts toward attaining opportunities for further consumer control of personal assistance services within the state.

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APPENDIX

METHODOLOGY

There were several components to this qualitative evaluation conducted by the Center on Human Policy.

1. Review of Documents. We reviewed various documents related to personal care services including: (a) policies and other written materials regarding the SDPS program from Enable and from the Long-Term Care office; (b) national information on "state-of-the-art" personal care services.

2. Interview Guide. Based on the review of documents, we developed three draft, open-ended interview guides, one for participants; one for PCAs; and one for administrators, Advisory Board members, and others.

3. Interviews with General Informants. Prior to conducting interviews with program participants and PCAs, we conducted eight general interviews with various people including: (a) the director of Enable; (b) the coordinator and assistant coordinator of the SDPS program at Enable; (c) an employee of the county Long-Term Care office; (d) an employee of the regional Developmental Disabilities Services Office; (e) two members Enable's SDPS Advisory Board; and (f) a local disability services advocate.

Based on the information gathered in these interviews, we revised the interview guides to incorporate issues raised by these informants.

4. Interviews with Program Participants. We interviewed a total of 16 program participants; 10 of these were selected randomly by the evaluation team; 5 additional people were selected by Enable's SDPS coordinator in order to ensure that we got some information about the program's support of people with diverse needs. Interviews were conducted both in person and by telephone, depending on the participant's preference. Most interviews were conducted in person.

5. Interviews with Personal Care Assistants and Self-Directing Others. We interviewed six randomly selected personal care assistants and three family members who were also self-directing others.

6. Identification of Themes and Issues. Across all of the data that were collected, we compiled the major themes and issues.

7. Preparation of Written Evaluation Report. The written evaluation report is based upon the major themes and issues that emerged from the data. A draft of the report was reviewed by all members of the Center on Human Policy research team, the director of Enable, the coordinator of Enable's SDPS program, and an administrator at the Long-Term Care office. The final product incorporates commentary from these people.